THE EFFECT OF POOR ADHERANCE TO TREATMENT OF PEOPLE LIVING WITH HIV/AIDS

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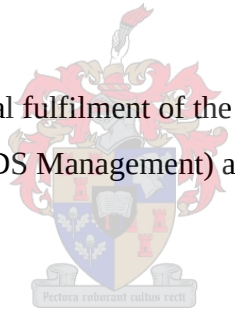

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DECLARATION

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January 2011

ABSTRACT

The purpose of this research was to identify the effect of poor adherence to treatment of people living with HIV/AIDS. Due to the rise in HIV/AIDS related deaths this study tried to establish whether the support systems of People living with HIV/AIDS (PLWA) are in line with the actual needs of PLWA to adhere to effective treatment therapy. The researcher made use of a semi-structured interview to collect the required information.

The findings of this study shows that certain obstacles prevent PLWA to adhere effectively to treatment and that these patients should be assisted in whatever way to overcome these obstacles to adhere effectively. Effective adherence to treatment therapy should further be enhanced through the implementation of good HIV/AIDS care practice that encourages patient involvement.

OPSOMMING

Die studie het ten doel om vas te stel waarom persone met MIV/VIGS nie gunstig op terapie reageer nie, asook om die uitwerking van hierdie ongunstige reaksie te bepaal. In die lig van die styging in MIV/VIGS verwante sterftes poog hierdie studie verder om vas te stel of die huidige ondersteuningsisteme van persone met MIV/VIGS voldoen aan die eintlike behoeftes van sodanige persone om optimale reaksie op terapie te verseker. Inligting is met behulp van `n semi-gestruktureerde onderhoud verkry.

Die studie het bevind dat sekere struikelblokke persone met MIV/VIGS verhoed om gunstig op terapie te reageer en dat sodanige persone ondersteun moet word om daardie struikelblokke te oorkom ten einde gunstige reaksie op behandeling te verseker. Hierdie ondersteuning behoort aangevul te word deur die instelling van gesonde MIV/VIGS ondersteuningspraktyke wat pasiënt-betrokkenheid insluit.

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References

1. Working title:

The effect of poor adherence to treatment of people living with HIV/AIDS.

2. Background:

Table 1: Global summary of the HIV/AIDS epidemic as per 2008 (UNAIDS 2009 November):

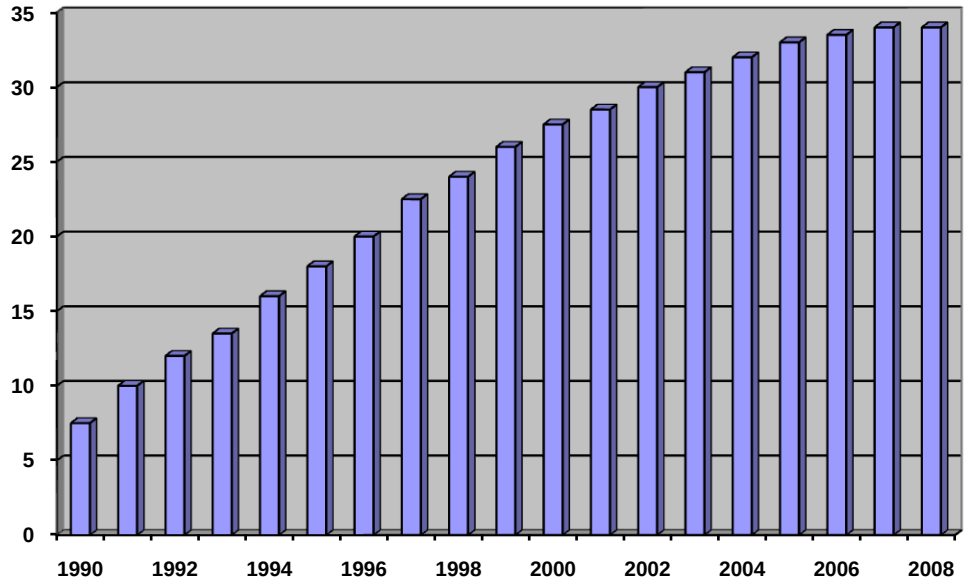
	Estimate	**Range**
People living with HIV/AIDS in 2008	33.4 million	31.1 – 35.8 million
Adults living with HIV/AIDS in 2008	31.3 million	29.2 – 33.7 million
Women living with HIV/AIDS in 2008	15.7 million	14.2 – 17.2 million
Children living with HIV/AIDS in 2008	2.1 million	1.2 – 2.9 million
People newly infected with HIV in 2008	2.7 million	2.4 – 3.0 million
Children newly infected with HIV in 2008	0.43 million	0.24 – 0.61 million
AIDS deaths in 2008	2.0 million	1.7 – 2.4 million
Child AIDS deaths in 2008	0.28 million	0.15 – 0.41 million

The following is of note:

- More than **25 million** people have died of AIDS since 1981.
- There are over **14 million** AIDS orphans in Africa.
- At the end of 2008, women accounted for more than **50%** of all adults living with HIV worldwide.
- In developing and transitional countries, **9.5 million** people are in immediate need of life saving AIDS drugs; of these, only **4 million** (42%) are receiving the drugs.

Global trends of people living with HIV

Figure 1



The number of people living with HIV has risen from around 8 million in 1990 to 33 million today, and is still growing. Around 67% of people living with HIV are in sub-Saharan Africa.

Table 2: Regional statistic for HIV & AIDS, end of 2008

Region	Adults &children living with HIV/AIDS	Adults & children newly infected	Adult prevalence*	Deaths of adults & children
Sub – Saharan Africa	22.4 million	1.9 million	5.2%	1.4 million
North Africa & Middle East	310, 000	35, 000	0.2%	20, 000
South and South- East Asia	3.8 million	280, 000	0.3%	270, 000
East Asia	850, 000	75, 000	<0.1%	59, 000
Oceania	59, 000	3900	0.3%	2, 000
Latin America	2.0 million	170, 000	0.6%	77, 000

Caribbean	240, 000	20, 000	1.0%	12, 000
Eastern Europe & Central Asia	1.5 million	110, 000	0.7%	87, 000
North America	1.4 million	55, 000	0.4%	25, 000
Western & Central Europe	850, 000	30, 000	0.3%	13, 000
Global Total	33.4 million	2.7 million	0.8%	2.0 million

***Proportion of adults aged 15 – 49 who were living with HIV/AIDS**

During 2008 more than two and a half million adults and children became infected with HIV (Human Immunodeficiency Virus), the virus that causes AIDS. By the end of the year, an estimated 33.4 million people worldwide were living with HIV/AIDS. The year also saw two million deaths from AIDS, despite recent improvements in access to antiretroviral treatment.

It should be noted that adults are defined as men and women aged 15 or above, unless specified otherwise. Children orphaned by AIDS are defined as people aged under 18 who are alive and have lost one or both parents to AIDS. Statistics utilized are global best estimates.

Sandstrom et al. (2003) found in their research that HIV/AIDS is the fourth most common cause of death in the world.

When analysing HIV/AIDS, significant data challenges are being identified. HIV/AIDS is a disease that remains at large misunderstood and it is also marked by significant social stigma. To be HIV-positive marginalises individuals from society, and bring shame and disrepute on their families. This leads to denial that is a common response and which in turn affects the identification and assessing of infection rates.

Ever since the first report about HIV/AIDS infection in the early 1980s, the spread of the HIV/AIDS epidemic has been an ever-present feature of world news.
This brings us to the question of what is HIV/AIDS about.

HIV/AIDS is an illness caused by a virus called the Human Immunodeficiency Virus (HIV) and it affects the human immune system by infecting the CD4+ cells, designed to combat infections. Once people are infected with HIV, they become prone to opportunistic infections. Tuberculosis is the most prominent infection. AIDS is diagnosed when a person diagnosed with HIV either becomes ill as a result of these infections, or when the number of CD4+ cells falls below a certain level.

Perelson et al. (1996) found that the HIV virus replicates at a high rate in untreated patients and when replication occurs during treatment, it leads to the development of genetic variation, which in turn leads to the emergence of variants that might be resistant to antiretroviral treatment (Coffin 1995).Germs/diseases spread and if the germs in the body have become resistant and spread to another person, they too will become ill.

Now what is resistance?

Resistance implies that the germs get used to the drugs and that it will then no longer be able to successfully fight the germs. The person will then become more ill, stay ill or even die.

The HIV virus easily becomes resistant to drugs and as such should People living with HIV/AIDS (PLWA) take their medication exactly as they are told. According to Bedell et al. (2000) only one-third of PLWA drink their medication as prescribed. Lerner, Gulick, Dubler (1998) found that although PLWA fully comprehend the consequences of non-adherence to medications, adherence rates are still suboptimal. When PLWA do not take their medication as the doctor prescribes, it is called non-adherence.

Non-adherence is dangerous and a risk to one's health. Non-adherence is normally caused by;

- People who don't take their medication three times per day as prescribed and at other times forget to take it.
- Sometimes people stop taking their medication as it leads to dizziness or nausea.

- Side-effects also do play a part in PLWA decision to stop taking their medication.
- People sometimes stop taking their medication when they feel better.
- People sometimes stop using the medication on the advice of friends who tell them that it is bad for their health.
- Sometimes they share their medication with others.

If people stop taking their medication they will become ill again and when they resume taking it the HIV virus will be more difficult to fight. The medication will not help them any more.

Antiretroviral adherence is the second strongest predictor of progression to AIDS and death, after CD4 count (Bangsberg et al. 2001). Adherence is defined by the World Health Organization (WHO) as; "the extent to which a person's behaviour – taking medication, following a diet, and/or executing lifestyle changes, corresponds with agreed recommendations from a health care provider" (WHO 2003).

While the disease is currently incurable, existing anti-retroviral therapy (ART) acts to inhibit opportunistic infections, and the onset of AIDS. The providing of antiretroviral therapy ensures a whole new social and economic context for people living with HIV since it allows for a productive life, averts premature death and prevents opportunistic infections (UNAIDS et al. 2000).

3. Research question:

Why do People that Live with HIV/AIDS (PLWA) not adhere to effective treatment therapy on HIV/AIDS and what can be done to discourage poor adherence?

Knowledge gap:

We do not know what PLWAs needs are regarding support use or the support services available to them. If this can be ascertained, the support services could be streamlined to meet the needs of the PLWA and so contribute to decreasing the numbers of PLWA who do not adhere to treatment therapy.

4. Significance of study:

This study will take place in the area of the Langeberg Municipality to establish whether the support systems of PLWA in this area are in line with the actual needs of PLWA to adhere to treatment therapy in order to identify shortcomings in the support systems.

5. Literature review:

The treatment of HIV/AIDS is for life and as such is the usage of HIV/AIDS medication a lifelong commitment. The rapid replication and mutation rate of HIV in this area (Langeberg Municipality) necessitates the need for this study. PLWA often stop taking their medication when they are feeling better and this kind of behaviour usually leads to non-adherence because they don't take their medication as medically prescribed.

The primary reason for not achieving the full health benefits medication can provide can be addressed to non-adherence. According to Yach in WHO (2003) poor adherence causes medical and psychosocial complications of disease, reduces patients' quality of life, increases the likelihood of development of drug resistance and wastes health care resources. These direct consequences, taken together impair the ability of health care systems around the world to achieve population health goals.

Sabatè stated in WHO (2003) that better adherence will not threaten health care budgets but that adherence to those medication already prescribed will lead to a significant decrease in the overall health budget. According to him this is due to the reduction in the need for more costly interventions, such as frequent and longer hospitalizations, unnecessary use of emergency room and highly expensive intensive care services. The rational use of medication means good prescribing and full adherence to the prescriptions.

a). Types of non-adherence:

Non-adherence can take many different forms (Miller 1997**)**. The patient may either fail to fill the prescription or time the medication incorrectly. Sometimes patients take the wrong dose because they misunderstood or forgot the health professional's instructions. Patients also tend to forget a dose completely or they terminate the

medication prematurely. Side-effects, toxicity and personal beliefs in many occasions lead to a self-adjustment in regimen.

b). Challenges in assessing adherence

Gao and Nau (2000) has found in their research that it is easy to miss adherence problems because patients tend to exaggerate their self-reports in a desire to please the provider and avoid criticism. Others might have done away with their medication before a scheduled check to appear as if they have adhered (Rand et al. 1992). Inadequate adherence coupled with biased reporting is ubiquitous across medication. On the other hand it appears as if patients who report problems with adherence do not mislead their providers (Wagner & Rabkin 2000).

Du Pasquier-Fediaevsky & Tubiana-Rufi (2002) found in their research that estimates of adherence made by health care providers are also usually over-optimistic. Health care providers are not very accurate in their prediction of which patients will adhere. Some do believe that factors such as lack of education and poverty are also good predictors of non-adherence. It is evident that predictors of adherence vary greatly across populations and settings and that factors associated with non-adherence differs across all studies (Chesney 2000).

c). Predictors of adherence

Four types of factors that have generally been found to predict problems with adherence to medication are: Regimen characteristics, various patient factors, the relationship between provider and patient and the system of care.

i). Regimen-related factors

a). Complexity of regimen.

Chesney, Morin & Sherr (2000) has found that adherence to HIV medications is an extremely complicated process and that effective drug therapy includes both the drugs themselves as well as adjustments to daily life such as requirements or restrictions on food intake and other activities. These adjustments together with problems of toxicity and side-effects can play a major role in an individual's willingness and ability to adhere to the therapy (Bartlett et al. 2000**)**.

Despite the fact that the effect of pill burden is closely associated with disease stage many health professionals believe that pill burden strongly influences adherence. Gao et al. (2000) found in their research that symptomatic individuals risk for complications of non-adherence to medication is higher than asymptomatic patients.

It appears that dosing schedules and food restrictions or requirements have a more permeable influence on adherence than pill burden. It appears that once-daily or twice-daily doses are preferred as found by Eldred et al. (1998) who reported that patients on twice-daily doses or less reported better adherence (>80%). This was confirmed by Paterson et al. (2000) who also found that patients with a twice-daily dose adhered better than patients with a three-times-daily dose.

Wenger et al. (1999) came to the conclusion that the "fit" of the regimen to an individual's lifestyle and schedule, as well as the individual's attitude towards treatment are better predictors of adherence than dosing schedule.

Halkitis P et al. (2003) found in their research that regimens that involve close monitoring; lifestyle alterations together with side-effects may not only frustrates patients but may lead to treatment fatigue and noncompliance. They concluded that regimens requiring fewer changes in lifestyle patterns have a positive influence on adherence to medication. Patients with strong biases against many pills and frequent dosing will benefit by reducing the number of pills and frequency of therapy, and minimizing drug interactions and side-effects. Stone et al. (1998) found that adherence improved by simplified regimens that require fewer pills and lower dose frequencies. Before any regimens are chosen it is important that the patient's eating habits should be reviewed and the specific food requirements discussed so that the patient understands what is required of him/her. Patients suffering from wasting will find regimens requiring an empty stomach several times per day difficult just as patients with fat aversion regimens requiring a high fat intake.

b). Side-effects.

Side-effects have also been consistently associated with decreased adherence. Stone **(**2001) found in his research that patients who experience more than two aversive reactions are less likely to continue their treatment therapy.

Patients quickly stop therapy or want to change their medication if they experience side-effects. Side-effects are responsible for more regimen changes than does treatment failure. D'Arminio et al. (2000) report in their research that more than 25% of treatment-naive patients do end their treatment within the first year of initiation of treatment due to toxicity and other side-effects. D'Arminio et al. (2000) found that fatigue, diarrhoea, nausea and stomach pain cause the most distress. Kasper et al. (2000) found that lipodystrophy plays a major role in the 37% of their respondents that either stopped or changed their medications.

ii). Patient-related factors

The critical link between a prescribed regimen and treatment outcome is a patient's behaviour and the most effective regimen will fail if the patient does not take the medication as prescribed or refuses to take it. Chesney (2000) concluded that consequently, all things being equal, the most important factors influencing adherence are patient-related.

a). Psychosocial issues.

Chesney (1997) found that life stress interferes with proper dosing of protease medication regimens and that such stress is often experienced by individuals of low socioeconomic status. Although studies of most demographic characteristics of patients have generally failed to establish consistent links with adherence to medication, research by Stone (2001) have described several variables that have a possible association. Adherence is apparently most difficult for patients with lower levels of education and literacy.

Halkitis, P. et al. (2003) have found that women have cited the stress of childcare as a reason for missing doses. Alcohol abuse, intravenous drugs and depressive symptoms also plays a part in poor adherence to medication.

Mocroft et al. (1999) demonstrated that although intravenous drug abusers were less likely to start with antiretroviral therapy, the response of those who did was similar to that of other exposed groups.

Psychological distress affect adherence. The most significant predictors of adherence are depression, stress, and the manner in which individuals manage stress. Hopelessness and negative feelings can reduce the motivation to care for oneself can be minimized by hopelessness and negative feelings and it may also influence a patient's ability to follow instructions.

Social support also affects adherence behaviour. Paterson et al. (2000) found that patients with support from friends and families tend to adhere to HAART better than those without these supports. They also concurs that in addition to the support of a good relationship between providers and patients, adherence can be improved by providing a telephone-counseling line where PLWA can left messages for nurses, and enlisting the support of pharmacists (Paterson et al. 1999). It is important for patients to involve family and friends in their care, and to follow up on referrals to support groups, peer-counseling and community-based organizations.

b). Patient-belief system.

The knowledge and beliefs about disease and medication can play a major role in adherence. Chesney et al. (2000) found in their research that a patient's understanding of the relationship between adherence and viral load and between viral load and disease progression plays a vital role in good adherence behaviour. Wenger et al. (1999) found that patients who believed antiretroviral medication to be effective adhere better.

Adherence behaviour can also be affected by confusion and difficulty in understanding instructions especially requirements and/or restrictions on the intake of food and water and temporal sequences of dosing. Patients may get confused because of the complexity of a regimen, and/or from poor instructions from the health care provider.

Chesney et al. (2000) found in their research that the most commonly cited reason for non-adherence is forgetfulness; for example, they reported that 66% of their respondents gave this as the main reason for their non-adherence.

iii). Patient–provider relationship.

A relationship between the patient and health care provider that is meaningful and supportive can help patients to overcome barriers to adherence. According to Chesney (2000) factors like perceptions of provider competence, quality and clarity of communication, compassion, involving the patient as an active participant in treatment decisions and convenience of the regimen are factors that strengthen the relationship between patient and provider. Patients become frustrated with health care providers when over misunderstandings when side-effects go unmanaged and especially when treatment becomes complex and the patient is blamed for being a "bad patient". These frustrations may lead to poor adherence.

6. Aim and Objectives

Aim:

Due to the rise in HIV/AIDS statistics the aim of this study is to establish whether the support systems of PLWA are in line with the actual needs of PLWA to adhere to effective treatment therapy.

Objectives:

The objectives of this study are;

- Levels of motivation and factors influencing PLWA to adhere to ARV treatment therapy.
- To establish why PLWA are using support system(s) in helping them to adhere to treatment therapy.
- PLWA requirements to enhance adherence to treatment therapy.
- To provide health care workers with possible guidelines to strategize effectively to help PLWA adhering to treatment therapy.

7. Research design and methods

Research design:

This study will take on the form of a qualitative study using a semi-structured interview.

Criteria for the target group:

- Age group 20 – 40
- Dependence on care givers for support and encouragement to take their medication
- Functionally Literate
- People living with Aids

Respondents who took part in this study:

Table 3: Respondents by age and gender – number and (%)

	Male	Female	Total
20-29 years	16 (32.0%)	16 (32.0%)	32 (64.0%)
30-40 years	10 (20.0%)	8 (16.0%)	18 (36.0%)
Total	**26 (52.0%)**	**24 (48.0%)**	**50 (100%)**

Method of data collection:

The **measuring instrument** was a self constructed semi-structured interview designed to establish whether the support systems of PLWA at the HIV/AIDS Clinic at Robertson Hospital are in line with their actual needs to adhere to treatment therapy. The clinic is a few metres away from the hospital. The respondents that met the study criteria were chosen with the help of the head of the clinic and after a review of the respondent's hospital records. The respondents completed an anonymous questionnaire that was handed out to them by the head of the clinic. The answered questionnaires were collected by the researcher after the respondents had placed these in a sealed box. The response rate was found to be 100%.

8. Data analysis and discussion

8.1 Levels of motivation and factors influencing PLWA to adhere to ARV treatment therapy

Data clearly shows that before starting with treatment 35(70.0%) of the respondents were very motivated to undergo treatment while 10(20.0%) were less motivated and 5(10.0%) were not motivated at all. This figure changed dramatically after the commencement of therapy with 94.0% of the respondents being motivated while 6.0% of the respondents remained unmotivated to adhere to treatment. This represents a significant increase of 24.0% in the respondents that are motivated in taking the medication. The reason for this change in motivation is due to the fact that according to them they feel better, healthier and stronger after taking the medication and that the problems which caused their non-adherence were looked after. The 6.0% who were less motivated felt that there was no change in their health and that they were still feeling the same as before taking the medication. This finding clearly shows that the level of a persons' motivation plays an important part in treatment adherence and that improvement in health is an important factor increasing levels of adherence. It also confirms the findings of Wenger et al (1999) who found better adherence in patients who believed antiretrovirals to be effective.

Motivation of respondents before starting with treatment

Table 4: Levels of motivation by gender – number and (%)

	Women	**Men**	**Total**
Very Motivated	20(40.0%)	15(30.0%)	**35 (70.0%)**
Less Motivated	0(0%)	10 (20.0%)	**10 (20.0%)**
Not Motivated	4(8.0%)	1(2.0)%	**5 (10.0%)**
Total	**24 (48.0%)**	**26 (52.0%)**	**50 (100%)**

Table 5: Levels of motivation by gender and age – number and (%)

Age & Sex	Very Motivated	Less Motivated	Not Motivated	**Total**
Males (20-29)	11 (22.0%)	5 (10.0%)	0(0%)	**16 (32.0%)**
Males (30-40)	4 (8.0%)	5 (10.0%)	1 (2.0%)	**10 (20.0%)**
Females (20-29)	15 (30.0%)	0(0%)	1 (2.0%)	**16 (32.0%)**
Females (30-40)	5 (10.0%)	0(0%)	3 (6.0%)	**8 (16.0%)**
Total	**35(70.0%)**	**10(20.0%)**	**5(10.0%)**	**50 (100%)**

This finding shows the following:

- Out of the 35(70.0%) highly motivated respondents 20(40.0%) were women and 15(30.0%) men. At the beginning women were more motivated than men to undergo treatment. The reason for this difference in motivation may be derived from the fact that women have families and have dependents. Right at the beginning men were less motivated than women due to the fact that they reported feeling strong and healthy and see treatment as a waste of time.
- From the very motivated males 11(22.0%) were from the age group 20-29 while 4(8.0%) were from the age group 30-40. The same scenario was found with the very motivated females where 15(30.0%) were from the age group 20-29 and 5(10.0%) from the age group 30-40. This shows that the younger respondents were found more eager to undergo treatment than the older respondents.
- The 10(20.0%) less motivated respondents were all men while the 5(10.0%) not motivated respondents consists of 1(2.0%) male and 4(8.0%) women.
- From the 4(8.0%) not motivate women only 1(2.0%) were from the age group 20-29 while the other 3(6.0%) were from the age group 30-40. This shows that the younger women were more motivated than the older women respondents to start with ARVs. One of the reasons for these findings may be that the younger respondents realised that their whole lives still lay ahead of them and that they will be able to lead a normal life with HIV/AIDS.

Motivation of respondents after starting with treatment:

Table 6: Levels of motivation by gender – number and (%)

		Women	**Men**
Very Motivated	47(94.0%)	27(54.0%)	20(40.0%)
Less Motivated	0(0%)	0(0%)	0(0%)
Not Motivated	3(6.0%)	2(4.0%)	1(2.0%)

Table 7: Levels of motivation by gender and age – number and (%)

	Age & Sex	Very Motivated	Less Motivated	Not Motivated
	Males (20-29)	16(32.0%)	0(0%)	0(0%)
	Males (30-40)	9 (18.0%)	0(0%)	1 (2.0%)
	Females (20-29)	16 (32.0%)	0(0%)	0(0%)
	Females (30-40)	6 (12.0%)	0(0%)	2 (4.0%)
Total	50	47(94.0%)	0(0%)	3(6.0%)

Table 8: Comparison between before and after starting with treatment therapy:

	Before	**After**
Very Motivated	35(70.0%)	47(94.0%)
Less Motivated	10(20.0%)	0(0%)
Not Motivated	5(10.0%)	3(6.0%)
Total	50(100%)	50(100%)

The abovementioned table shows an increase of 12(24.0%) respondents which boosted the very motivated respondents to a total of 47(94.0%), Out of the increase of 12(24.0%) respondents 7(14.0%) were women and 5(10.0%) were men. The reason for this change in motivation can be found in the fact that the respondents felt better and healthier after taking the medication as well as the fact that others – doctors,

nurses, counsellors and family members - were also interested in their wellbeing. They also reported high levels of lifestyle change by reducing alcohol intake and adhering with the scheduled intake of the prescribed medication. This data clearly shows that some time after taking the medication the older men respondents 9(18.0%) were more motivated to go on with the treatment therapy than the women respondents of the same age 6(12.0%). The male and female respondents in the age group 20 – 29 were evenly motivated to continue with the treatment therapy - total of 16(32.0%).

8.2 Why PLWA are using support systems in helping them to adhere to treatment therapy

The reason for the rise in the adherence percentages can clearly be related to the human factor, the respondents were encouraged by care-givers to overcome the problems that were causing non-adherence. Out of the 50 respondents, 26(52.0%) respondents stated that they experienced problems right at the start when it comes to taking ARVs while 24(48.0%) respondents did not experience any problems.

The 26(52.0%) respondents express the following main reason for not taking the prescribed medication:

- A shortage of money to buy food as some medication require a full stomach 4(8.0%),
- A shortage money to pay for their taxi-fare since the clinic is not in walking distance of their homes 3(6.0%)
- Forgetfulness 2(4.0%).
- Side-effects 3(6.0%)
- Stigmatisation 3(6.0%)
- Change in lifestyle 3(6.0%)
- Alcohol abuse 3(6.0%)
- Hopelessness and negativity 2(4.0%)
- The belief that they will eventually die of HIV/AIDS and that the medication only give them time to get their personal stuff in order so that their kids will be looked after when they eventually dies 1(2.0%)
- Hopelessness and negative feelings that reduce the motivation to care for one and which also influences the patient's ability to follow complex instructions

2(4.0%).These findings corresponds with studies by Chesney et al. (2000) which demonstrated a relationship between adherence and depression.

This study clearly shows that side-effects are also responsible for the drop in the adherence percentage of males and female age 30 – 40. In this case 2(4.0%) of the women respondents age 30 – 40 years failed to take a dose during the last month due to side-effects causes by the medication. This finding corresponds with the findings of Chesney (2000) who found in his research that adherence is reduced by medications that produce side-effects. This finding also corresponds with the findings of Kasper et al. who found that (37.0%) respondents either stopped or changed their medication due to side-effects. From those respondents who were adherent (57.0%) stated serious consideration of discontinuation of the medication while some (46.0%) acknowledge that they would stop if the symptoms worsened. It also corresponds with the findings of Chesney (2000) who found better adherence in patients with simplified regimens that require fewer pills and lower dose frequencies.

In terms of breakdown of results by age, older respondents 17(34.0%) experience more problems than the younger respondents in adhering to treatment 9(18.0%). Problems that elderly respondents experience are:

- A shortage of money to buy food as some medication require a full stomach 5(29.5%)
- A shortage money to pay for their taxi-fare since the clinic is not in walking distance of their homes 3(17.6%)
- Forgetfulness 3(17.6%)
- Side-effects 3(17.6%)
- Believe they will eventually die 1(5.9%)
- Hopelessness and negativity 2(11.8%)

The greatest problems of younger respondents are:

- Stigmatisation 3(33.3%) and
- Change in lifestyle 3(33.3%).
- Alcohol abuse 3(33.3%)

Table 9: Factors enhancing non adherence for elderly respondents – number and (%)

	Males (20 – 29)	**Males (30 – 40)**	**Female (20 – 29)**	**Females (30 – 40yr.)**
Food Shortage	0(0%)	2(11.8%)	0(0%)	3(17.6%)
Transport Fee	0(0%)	1(5.9%)	0(0%)	2(11.8%)
Forgetfulness	0(0%)	2(11.8%)	0(0%)	0(0%)
Side-effects	0(0%)	2(11.8%)	0(0%)	2(11.8)%
Believe they'll eventually die	0(0%)	1(5.9%)	0(0%)	0(0%)
Hopelessness & negativity	0(0%)	2(11.8 %)	0(0%)	0(0%)

Table 10: Factors enhancing non adherence for younger respondents – number and (%):

	Males (20 – 29)	Males (30 – 40)	Female (20 – 29)	Females (30 – 40yr.)
Stigmatisation	1(11.1%)	0(0%)	2(22.2%)	0(0%)
Lifestyle change	2(22.2%)	0(0%)	1(11.1%)	0(0%)
Alcohol abuse	2(22.2%)	0(0%)	1(11.1%)	0(0%)

8.3 PLWA requirements to enhance adherence to treatment therapy

Chesney et al. (2000) found that a patient's knowledge and beliefs about disease and medication can influence adherence. Here the role as well as the attitude of the person who gave the information when starting the first treatment whether it is the doctor, nurse or counsellor is of great importance.

In the case of information supplied before starting the treatment the following percentages were found.

- 30% by the counsellor
- 50% by the sister
- 20% by the doctor

This clearly shows that more respondents get their information from the sister mainly because she tested them for HIV/AIDS, followed by the counsellor and then the doctor.

Table 11: Information suppliers

Counsellor	Doctor	Sister (Nurse)
15(30.0%)	10(20.0%)	25(50.0%)

This study also shows that:

- 30(60.0%) of the respondents prefer to get their information from the person who initially supplied them with information be it either the counsellor, doctor or nurse because he/she:
    - Had the right attitude
    - Understands them and their fears
    - Has patience and
    - shows a caring attitude while
    - 20(40.0%) of the respondents prefer to get their information from another source because of experiencing a harsh and uncaring attitude whether it be the counsellor, doctor or nurse

This study shows that:

- 5(10.0%) of the respondents makes a habit of not adhering to treatment because they don't want to take the medication.
- 26(52.0%) of the respondents sometimes forgot to take their medication due to the following reasons:
    - A shortage of money to buy food as the intake of some medication requires a full stomach -5(10.0%) – young and old men and women.

- A shortage money to pay for their taxi-fare since the clinic is not in walking distance of their homes -3(6.0%) mainly older women
- Forgetfulness -3(6.0%) older men and women.
- Side-effects -3(6.0%) older men and women
- Stigmatisation -3(6.0%) younger men and women
- Change in lifestyle -3(6.0%) young men and women
- Alcohol abuse -3(6.0%) mainly young men
- The belief that they will eventually die of HIV/AIDS and that the medication only give them time to get their personal stuff in order so that their kids will be looked after when they eventually dies -1(2.0%) mainly older men.
- Hopelessness and negative feelings that reduce the motivation to care for one and which also influences the patient's ability to follow complex instructions 2(4.0%) mainly older men.

- 19(38.0%) of the respondents make sure that they remember to take their medication or ask someone to remind them to take their medication.

During this study 43(86.0%) of the respondents genuinely believe that the treatment as well as seeing to the abovementioned "problems" will prevent them from becoming ill rapidly as a result of HIV/AIDS while 7(14.0%) believes otherwise. Of the 43(86.0%), 30(60.0%) are women and 13(26.0%) are men. More young men and women believe that the treatment will work because they feel healthier and better after taking the medication. The older men on the other hand feel that the treatment will not work because they believe that they will eventually die of HIV/AIDS and that the medication only give them time to get their personal affairs in order so that their kids will be looked after when they eventually dies.

This clearly shows that the person who supplies the patient with information right at the start needs to play a caring and understanding role in the patient's life. He should be able to understand his patient's needs and shortcomings and encourage him or her to adhere no matter the cost. The caregiver should also be in close contact with the patient's family to help identify possible problems that would handicap the patient in trying to adhere to therapy and to help the patient in finding possible solutions.

8.4 Guidelines to strategize to help PLWA adhering to treatment therapy

Shortcomings identified through this study in the support systems indicate that a multifaceted approach to improve adherence is the most likely to be beneficial. This study further points out that patients must be given a chance to be actively involved in decisions that concerns their health This involvement by the patient should be combined with appropriate support, multidimensional educational programmes that teach behavioural skills to enhance adherence, together with the tailoring of the regimen to fit the patient.

Together with the abovementioned, the role of the person who gives the information in the first instance – nurse, doctor or counsellor - to the patient is of utmost importance. He or she should show a caring attitude towards the patient as well as a genuine interest in the wellbeing of the patient. Spot checks must be the order of the day to make sure that the patient takes his medication as prescribed irrespective of the factors that discourages them not to take their medication.

It would also be best for the patient-provider relationship if the health practitioner works together with the patient to select a regimen that will fit his or her lifestyle. Where it seems that more than one regimen may be appropriate, providers may want to discuss the regimen, the quantity of pills, the dosing schedule, instructions and potential side effects with the patient. Patients should therefore be helped and strategies provided to help them manage any side-effects that may occur because side-effects as seen above are usually associated with non-adherence. It is essential for an effective patient-provider relationship that the providers and their team members should remain in close contact with the patient during early treatment with a new regimen to allow for the timely identification and management of all side-effects and toxicities. Such close contact can be advantageous in reinforcing adherence behaviour. It is of great importance that health care providers and their teams should address the patient-related factors and psychosocial issues associated with non-adherence as soon as possible after a regimen is decided upon.

This handling of the situation will lead to a more appropriate and collaborative relationship between the practitioner and the patient. This action will in all likelihood enhance adherence.

Adherence can also be greatly enhanced by the support of family members and "significant others", or employing "treatment buddies" to administer medications. Patients must be encouraged to get such help from their families and friends and on the other hand families and friends must also be encouraged to get involved.

Last but not least, regular and positive feedback is regarded as one of the powerful reinforcers of adherence behaviour. To enhance good adherence behaviour feedback should be conducted soon after the initiation of treatment to show the extent to which it has been effective. Communication and the managing of it play a vital role in getting PLWA to adhere. Patients should always be encouraged to never give up hope.

9. Conclusion

This study shows that adherence is clearly the important factor in managing HIV/AIDS and how important it is that the patient should be assisted in whatever way to overcome the obstacles that prevent him/her from adhering to ARV treatment. The patient should be clear about the importance of adhering as well as the seriousness of the consequences when not adhering.

To fight effectively against this disease it is necessary to implement projects of good HIV/AIDS care practice that encourages patient-involvement.

References

Adherence to long-term therapies - Evidence for action. Geneva:
World Health Organization; 2003.

Bangsberg DR, Perry S, Charlebois ED, Clark RA, Roberston M, Zolopa AR, Moss A. Non-adherence to highly active antiretroviral therapy predicts progression to AIDS. Aids 2001; 15:1181-3.

Bartlett J, DeMasi R, Quinn J,Moxham C, Rousseau F. (2000). Correlation between antiretroviral pill burden and durability of virologic response: a systematic overview. Program and abstracts of the XIII International AIDS Conference; 9–14 July, 2000; Durban, South Africa.Abstract ThPeB4998.

Bedell SE et al. (2000). Discrepancies in the use of medications: their extent and predictors in an outpatient practice. Archives of Internal Medicine.

Carr, A. et al. (1998) A syndrome of peripheral lipodystrophy, hyperlipidaemia and insulin resistance in patients receiving HIV protease inhibitors. AIDS. 12:F51–F58.

Catz SL et al. (2000). Patterns, correlates, and barriers to medication adherence among persons prescribed new treatments for HIV disease. Health Psychology. 19:124–133.

Chesney MA, Morin M, Sherr L. (2000). Adherence to HIV combination therapy. Social Science & Medicine. 50:1599–1605

Chesney MA et al. (2000). Self-reported adherence to antiretroviral medications among participants in HIV clinical trials: the AACTG adherence instruments. AIDS Care. 12:255–266.

Creswell, J. W. (1998). Qualitative inquiry and research design: Choosing among five traditions. Thousand Oaks, Ca: Sage.

Cormack, D.S. (1991). The research process. Black Scientific: Oxford.

D'Arminio A et al. (2000). Insights into the reasons for discontinuation of the first highly active antiretroviral therapy (HAART) regimen in a cohort of antiretroviral naïve patients. AIDS. 14:499–507.

Du Pasquier-Fediaevsky, L. & Tubiana-Rufi, N. (2002). Discordance between physician and adolescent assessments of adherence to treatment: influence of HbA1c level. Diabetes Care, 22: 1445 – 1449.

Duran S et al. (2001) Self-reported symptoms after initiation of a protease inhibitor in HIV-infected patients and their impact on adherence to HAART. HIV Clinical Trials. 2:38–45.

Farmer P, Le´andre F, Koenig S, et al. Preliminary outcomes of directly observed treatment of advanced HIV disease with ARVs (DOTHAART) in rural Haiti [abstract

171]. In: Program and abstracts of the 10th Annual Conference on Retroviruses and Opportunistic Infections (Boston). Alexandria, VA: Foundation for Retroviruses and Human Health, 2003:120. Available at http://www.retroconference.org/ 2003/Abstract/Abstract.aspx?AbstractIDp2135.

Gao X et al. (2000). The relationship of disease severity, health beliefs and medication adherence among HIV patients. AIDS Care. 12:387–398.

Gordillo V et al. (1999). Sociodemographic and psychological variables influencing adherence to antiretroviral therapy. AIDS. 13:1763–1769.33.

Halkitis P et al. (2003). Characteristics of HIV antiretroviral treatments and adherence in an ethnically-diverse sample of men who have sex with men. AIDS Care (in press).

Eldred LJ et al. (1998). Adherence to antiretroviral and pneumocystis prophylaxis in HIV disease. Journal of Acquired Immune Deficiency Syndromes. 18:117–125.

Ickovics, J.R., & Rodin, J. (1992). Women and AIDS in the United States: epidemiology, natural history, and mediating mechanisms. Health Psychology, 11, 1-16.

Kasper TB, Arboleda CH, Halpern M. (2000). The impact of patient perceptions of body shape changes and metabolic abnormalities on antiretroviral therapy.

Lerner BH, Gulick RM, Dubler NN. (1998). Rethinking nonadherence: historical perspectives on triple-drug therapy for HIV disease. Annals of Internal Medicine. 129:573–578.

Miller NH. Compliance with treatment regimens in chronic asymptomatic diseases. American Journal of Medicine, 1997, 102:43–49.

Mocroft A et al. (2001). Reasons for modification and discontinuation of antiretrovirals: results from a single treatment centre. AIDS. 15:185–194.

Murphy DA et al. Antiretroviral medication adherence among the REACH HIVinfected adolescent cohort in the USA. AIDS Care, 2001, 13:27–40.

Nieuwkerk T, Gisolf EH, Wu AW. (2000) Quality of life in asymptomatic- and symptomatic HIV infected patients in a trial of ritonavir/saquinavir therapy. AIDS. 14:181–187.

Panel on Clinical Practices for Treatment of HIV. Guidelines for the use of antiretroviral agents in HIV-infected adults and adolescents (NIH 2002). Morbidity and Mortality Weekly Report. Atlanta, GA, Centers for Diseases Control and Prevention, 2002,Vol. 51, No. RR07.

Paterson DL et al. (2000). Adherence to protease inhibitor therapy and outcomes in patients with HIV infection. Annals of Internal Medicine. 133:21–30.

Rand CS et al. Metered-dose inhaler adherence in a clinical trial. American

Review of Respiratory Disease, 1992, 146:1559–1564.

Reiter GS et al. Elements of success in HIV clinical care: multiple interventions that promote adherence. Topics in HIV Medicine, 2002, 8: 21-30.

Rubin, H.J. & Rubin, I.S. (2004). Qualitive Interviewing. The art of hearing data. 2nd Edition. Sage

Stone V. (2001). Strategies for optimizing adherence to highly active antiretroviral therapy: Lessons from research and clinical practice. Clinical Infectious Diseases. 33:865–872.

UNAIDS et al. (2000). The Business Response to HIV/AIDS: Impact and Lessons Learned, Geneva and London.

UNAIDS 2009 November

Wagner GJ, Rabkin JG. Measuring medication adherence: are missed doses reported more accurately then perfect adherence? AIDS Care, 2000, 12:405–408.

Wenger N et al. (1999). Patient characteristics and attitudes associated with antiretroviral (AR) adherence.Abstract No.98. Presented at the VI Conference on retrovirus and opportunistic infections. Washington DC.